

ORIGINAL RESEARCH

Quality of Life of Persons with Disabilities in Southern Nations, Nationalities, and Peoples' Region, Ethiopia

Judith Baart^{1*}, Alice Schippers², Mamush Meta³

1. Research and Documentation Specialist, Light for the World, Netherlands

2. Executive Director, Disability Studies in Nederland, Amsterdam UMC, Netherlands

3. Coordinator, Regional Disability Mainstreaming Programme, Ethiopian Centre for Disability and Development, Ethiopia

ABSTRACT

Purpose: *There is very little demographic or prevalence data regarding persons with disabilities in Ethiopia, let alone data on more in-depth factors such as access to services or quality of life. This study aimed to find out about the current quality of life of persons with disabilities in Southern Nations, Nationalities, and Peoples' Region (SNNPR), Ethiopia.*

Method: *The WHO CBR Indicator Survey was used to measure quality of life, and the Washington Group Short Set was included to allow disaggregation of the data by different types of functional limitations. Interviews were conducted with 966 persons with disabilities in 10 towns in SNNPR. The majority of data collectors were persons with disabilities themselves.*

Results: *People with disabilities who were surveyed generally regarded their health as good (65.9%). Very few had significant levels of education (16.5% were completing higher education). Only 6.7% were working for wages and 45.2% were reportedly working on their own account. Hardly any of them (2.9%) stated that their money was sufficient for their needs. Only a small group (38%) felt valued in their community. Just over half of the respondents (56.6%) were members of a Disabled Persons' Organisation (DPO) or any other self-representing group.*

Conclusion: *Persons with disabilities scored relatively or extremely low in all areas of life measured with the CBR Indicator Survey (health, education, livelihood, social and empowerment). The survey will be repeated after a few*

* **Corresponding Author:** Judith Baart, Research and Documentation Specialist, Light for the World, Netherlands.
Email: judith.melanie@gmail.com

years in the same communities to measure changes over time, and persons without disabilities will be included in order to draw comparisons.

Implications: *Public and private organisations in SNNPR need to become more accessible and inclusive of persons with disabilities so as to improve their quality of life.*

Key words: *Education, health, livelihood, Disabled Persons' Organisations, access.*

INTRODUCTION

The Southern Nations, Nationalities, and People's Region (SNNPR) is one of the nine ethnically-based regional states of Ethiopia. Located in the Southern and South-Western parts of the country, it accounts for nearly 20% of the total population. This is one of the most populous regions of Ethiopia, with over 150 persons per square kilometre.

In 2017, the SNNPR regional government, in partnership with the Ethiopian Centre for Disability and Development (ECDD), started the Regional Disability Mainstreaming (RDM) Programme, funded by Light for the World and Irish Aid Ethiopia. The RDM Programme seeks to improve the lives of persons with disabilities by working with various government bureaus and non-government agencies and actors that are present in the region, ranging from schools and village savings and loan associations to businesses, development NGOs and government bureaus. The rationale is that if the service delivery and programmes of these agencies and organisations are more accessible and inclusive of persons with disabilities, then the quality of life of individual persons with disabilities will improve.

Objective

Conceptually, Quality of Life is “usually a number of variables across a variety of life areas working in an interrelated fashion” (Schipper et al, 2015). Quality of Life Measurement Instruments are generally characterised by using a changing number of indicators across a variety of life domains, as summarised in Schippers et al (2015). The Community Based Rehabilitation (CBR) Matrix (World Health Organisation, 2010) is no different: it illustrates five key life domains – health, education, livelihood, social and empowerment – which influence an individual’s life, depending on their access to and decision-making power over these components. These five domains are the focus of work for many disability, development and rehabilitation

organisations in developing countries such as Ethiopia, and are therefore logical life domains to use when assessing quality of life there.

However, data about persons with disabilities is hardly available in Ethiopia. There is no agreement on prevalence of disability (Dutch Coalition on Disability and Development, 2019), and existing household surveys such as the Demographic and Health Survey (Central Statistical Agency, 2017) do not measure or disaggregate data by disability. Going beyond prevalence, this means there is little or no information on access to services, financial independence, community participation or otherwise, for persons with disabilities. In most low- and middle-income countries, such as Ethiopia, there is hardly any up-to-date data on prevalence of persons with disabilities, let alone on their access to services and quality of life. Yet this data is important and necessary in order to understand where to focus advocacy efforts for change in policy and practice. In addition, an understanding of the current quality of life of persons and their access to services – disability-focussed or otherwise – can give organisations and government agencies working in SNNPR an indication of where to make a start to improve the lives of children, youth and adults with disabilities and their families.

Thus, this study aims to answer the question, “What is the current quality of life of persons with disabilities in Southern Nations, Nationalities, and Peoples’ Region, Ethiopia?”

METHOD

Study Tool

Given that the CBR Matrix had already been translated into a ready-to-use tool, the CBR Indicator Survey (WHO, 2015) was a logical choice to measure the quality of life of persons with disabilities in the Ethiopian region of SNNPR. This study used the WHO CBR Indicators survey, a multiple-choice question survey, adding a few questions to the existing list as well as removing several which did not fit the Ethiopian context. The Washington Group Short Set of questions was also added to the survey, to allow disaggregation of the data by different types of functional limitations. For example, “Do you have difficulty walking or climbing steps?” was of one of the Washington Group questions. Each individual who responded ‘Some difficulty’, ‘A lot of difficulty’ or ‘Cannot do at all’, was counted as having a functional limitation for that category.

Data collection was done using the Kobo Collect app for Android. Data was collated and analysed quantitatively in Microsoft Excel.

Data Collectors

Twenty data collectors (1 male and 1 female for each of the 10 target towns) were recruited for this study. Most of them were persons with disabilities and were, at the minimum, secondary school graduates with some knowledge of English. Data collectors were provided with Samsung Android Tablets to record questionnaire responses and were given 1-day training in the use of the Tablet questionnaire, with follow-up field support by RDM staff.

The questionnaire was provided in English and Amharic, and in some cases data collectors verbally translated the questions to a local language for the respondents to understand better.

Each data collector identified and interviewed a minimum of 48 respondents, selected according to the criteria described below.

Study Sample

The survey was carried out in 10 towns of varying sizes in SNNPR: Hawassa, Leku, Chuko, Aleta Wondo, Wendo Genet, Yirgalem, Durame, Butajira, Wolayita Sodo and Arba Minch. A “purposeful” sample of persons with disabilities was recruited (Palinkas et al, 2015).

Data collectors were encouraged to identify and interview an equal number of male and female participants, as well as an equal number of individuals with different ‘types’ of disabilities, such as visual, hearing, mobility and intellectual impairments. There were no age restrictions. Respondents were identified through local Disabled Peoples’ Organisations or the local Agency of Labour and Social Affairs office, and all those identified as having a disability. A total of 966 individuals were interviewed – roughly 96 per town. Proxy interviews were carried out with 5 of the respondents, in the case of intellectual impairment or where respondents did not have sign language skills.

The authors chose not to interview persons without disabilities for comparison purposes due to budget constraints.

Ethical Considerations

The survey followed the Disability Studies in the Netherlands (2017) Code of

Practice for Researchers. The data collectors explained the purpose of the study and consequences of participation to each respondent, in a manner they could understand. Each respondent who agreed to participate signed a Consent Form, which included the statement that withdrawal from the study was possible at any time. Anonymity of responses was maintained. Research data was stored securely and access was limited to prevent disclosure of sensitive information. Officials of the Agency of Labour and Social Affairs (ALSA) at Regional level and in each town were informed about the survey in writing, and assistance in identifying potential respondents was requested.

RESULTS

Interviews of 966 persons – 579 men, 386 women and 1 unspecified individual – were conducted for the survey. Of these, 242 respondents (25%) were under 18 years of age and the remaining 724 (75%) were above 19 years.

Functional limitations and living situation of the respondents is presented first, followed by key indicators of the WHO CBR Indicator Survey for each of the five domains in the survey: health, education, livelihood, social and empowerment. The entire research results for all indicators can be found in ‘Quality of Life of Persons with Disabilities in SNNPR, Ethiopia’ (Ethiopian Centre for Disability and Development, 2018).

Socio-demographic Characteristics of the Study Population

Although all the interviewed respondents had self-identified as persons with disabilities, 2.1% indicated that they did not have any difficulty in functioning. Just over half of them (51.4%) had difficulty in one of the domains of functioning (i.e., difficulty seeing, hearing, walking, remembering, self-care or communication). The rest indicated that they had difficulty functioning in two or more domains, the results being respectively 26.2% for 2 domains, 12.4% for 3 domains, 5.9% for 4 domains, 1.8% for 5 domains, and 0.2% of respondents indicated that they had difficulty functioning in all domains of the Washington Group Short Set (Table 1).

With regard to ‘type’ of functional limitations as reported by the respondents, 26% indicated they had difficulty seeing, 24% reported difficulty hearing, 54% had difficulty walking, 26% had difficulty remembering, 25% had difficulty with self-care and 19% had difficulty communicating. This reflects the purposeful sampling method that was followed, whereby care was taken to involve persons with all types of disabilities, rather than reflecting the actual distribution of types of functional limitations throughout the population of SNNPR.

The majority of persons with disabilities (81%) reported that they lived with their families, while the rest stated that they lived with other family members (6%), with someone else (5.2%) or on their own (7.8%).

Table 1: Functional Limitations and Living Situation of the Study Population

	Categories	Count (n=966)	Percentage
Number of respondents with each type of functional limitation¹	Difficulty seeing	251	26%
	Difficulty hearing	234	24%
	Difficulty walking	524	54%
	Difficulty remembering	252	26%
	Difficulty with self-care	245	25%
	Difficulty communicating	182	19%
Number of different functional limitations	0	20	2.1%
	1	497	51.4%
	2 ²	253	26.2%
	3	120	12.4%
	4	57	5.9%
	5	17	1.8%
	6	2	0.2%
Living Situation (n=965)	Living with parents	782	81%
	Living with other family members	58	6%
	Living on one's own	75	7.8%
	Living with someone else	50	5.2%

1. A functional limitation is defined as having difficulty in carrying out a universal basic activity. Individuals could have functional limitations in more than one category.
2. Common functional limitations that were found together include difficulty hearing and difficulty communicating; difficulty remembering and difficulty with self-care; and difficulty remembering and difficulty communicating.

Health

Over half of the persons with disabilities (68.5% for men and 62% for women) considered their health to be good or very good. In addition, 66% of all respondents felt they were treated with respect when they had last visited a healthcare provider (Table 2).

Table 2: Health Indicators

Health	Male (count / %)	Female (count / %)	Total (count / %)
% who rate their health as good or very good	396 / 68.5%	239 / 62%	635 / 65.9%
% who rate experience of being treated with respect at last visit to healthcare provider as good or very good	370 / 66.5%	245 / 66%	615 / 66.4%

Education

Only 37.5% of boys and 69.6% of girls with disabilities (7-12 years of age) are attending or have completed primary education. The figure is lower for the youth (13-18 years of age) who are attending or have completed secondary education (18.2% for males and 24.6% of females). In both cases the number of respondents in the age group was relatively low and therefore not statistically relevant (Table 3).

Given that it is a rarity for youngsters with disabilities to complete primary and secondary education, it is not surprising that among adults aged 19 years and above, only 16.8% of men and 16.2% of women are attending or have completed some form of higher education, including vocational training, skills training, or college. The majority (85.3% of males and 83.3% of females) have received education in a mainstream education facility.

Table 3: Education Indicators

Education	Male (count / %)	Female (count / %)	Total (count / %)
% of children with disabilities ³ attending or completing primary education	15 / 37.5%	24 / 68.6%	39 / 52%
% of youth with disabilities attending or completing secondary education ⁴	14 / 18.2%	17 / 24.6%	31 / 21.2%
% attending or completing higher education ⁵	75 / 16.8%	44 / 16.2%	119 / 16.5%
% who acquire education in mainstream education facilities ⁶	434 / 85.3%	274 / 83.3%	708 / 84.5%

3. Aged 7 -12 years

4. Aged 13-18 years

5. Aged 19+ years

6. Government or private school/institution

Livelihood

Slightly less than half of the respondents indicated that they were self-employed, were working in the family business, or were working in a group income-generating activity (Table 4). The figure was 46.4% for men and 40.3% for women. Only 8% of men and 4.6% of women reported working for wages with an employer. Hardly any of these activities seem to translate into significant income as only 3% of men and 2.7% of women indicated that they had enough money to meet their needs most or all of the time.

Table 4: Livelihood Indicators

Livelihood	Male (count / %)	Female (count / %)	Total (count / %)
% who are self-employed or own account workers	243 / 46.4%	130 / 40.3%	373 / 45.2%
% who are working for wages or salary with an employer	40 / 8%	15 / 4.6%	55 / 6.7%
% who have enough money to meet their needs	17 / 3%	10 / 2.7%	27 / 2.9%

Social

With regard to social indicators, only a small group (40.5% of men and 34.3% of women) indicated that they felt valued as individuals by members of their community (Table 5).

Table 5: Social Indicators

Social	Male (count / %)	Female (count / %)	Total (count/%)
% who feel valued as individuals by members of their community	233 / 40.5%	132 / 34.3%	365 / 38%

Empowerment

Disabled Persons' Organisations (DPOs) or parents' groups are organisations where persons with disabilities can convene and plan disability rights advocacy and other activities. For parents it is an opportunity to share experiences, so that others know that they are not alone. It was reported by 56.8% of men and 56.2% of women that they belonged to or participated in such a group or organisation (Table 6).

Table 6: Empowerment Indicators

Empowerment	Male (count / %)	Female (count / %)	Total (count/%)
% who belong to or participate in a local group or organisation of persons with disabilities (DPO) or parents' group	329 / 56.8%	217 / 56.2%	546 / 56.6%

DISCUSSION

The goal of this study was to understand the current quality of life for persons with disabilities in SNNPR, Ethiopia. Therefore, persons with disabilities were asked how they score in different areas of life, namely health, education, livelihood, social and empowerment. Several key indicators in these five areas of life have been presented in the results, although many more were measured.

The following discussion reflects on several striking aspects of the results.

Despite the fact that Ethiopia invests in the inclusion of children with disabilities in the primary education system, very few persons with disabilities have progressed beyond elementary level.

Education is a major predictor for quality of life in general, and quality education even more so (UNESCO, 2004). The results show that very few persons with disabilities progress beyond elementary school education. The majority of those who pursue any form of education do so in a mainstream education facility. This reflects the fact that Ethiopia has been promoting inclusive education and investing in children with disabilities within the primary education system – government statistics stating that 14,225 primary schools in the country provide special needs education (Federal Democratic Republic of Ethiopia Ministry of Education, 2016). Despite this, and reflecting the study data which shows that few progress beyond elementary level, many children with disabilities do not enrol for primary education or progress higher in education as many schools are not accessible to, open to, and adapted, or welcome and support children with disabilities (Tefera et al, 2015).

Although almost half of the persons with disabilities reported pursuing an occupation in the form of self-employment, this does not lead to reporting that they have a decent livelihood.

The survey data may give the impression that many persons with disabilities have a decent livelihood, as almost half of them indicated they were currently self-employed or working on their own account. This conclusion may be inaccurate. Own account workers include those working at income-generating activities or in family businesses, and those identifying themselves as self-employed. However, research shows that the self-employed are mostly, and particularly in Sub-Saharan Africa, subsistence entrepreneurs, that is “those who are self-employed out of necessity and who often lack skills and entrepreneurial traits”

(Cho et al, 2016). Many of the self-employed are poor (Cho et al, 2016), report lower income and are less educated than those that work for an employer or even the rest of the general population (Ryan, 2014). Self-employment, or own account work, is thus often not a choice, but a necessity because employers often refuse to employ a person with a disability, or individuals cannot find other activities to generate an income (Ryan, 2014; Cho et al, 2016). This corresponds to the results of the current study. Despite the fact that more than half of the persons with disabilities engage in self-employment or other forms of own account work, only 2.9% of respondents indicated that they had enough money to meet their needs, and only 6.7% reported that they work for an employer. Persons with disabilities in SNNPR generally work at subsistence level, most likely out of necessity, as they are not able to find work that provides a decent income.

The participation of persons with disabilities and Disabled Persons' Organisations in the data collection phase of the survey has greatly increased visibility of both persons with disabilities and their organisations.

The participation of 10 local DPOs in the target towns of the survey in identifying survey respondents, greatly increased their visibility to both government officials and members of the public. This contributed to greater government support for some of the DPOs, as well as inclusion of their representatives in local decision-making processes introduced by the RDM Programme. In addition, persons with disabilities were specifically included in the research in the role of data collectors. Inclusive research is that which “involves people who may otherwise be seen as subjects of the research, as instigators of ideas, research designers, interviewers, data analysts, authors, disseminators and users” (Nind, 2017). Employing researchers similar to respondents in field work, has been found to benefit research results because respondents feel they can be “more open and frank with researchers they feel can empathise with their situation” (National Disability Authority, 2002). In addition, including an equal number of female data collectors with disabilities facilitated interviews with female respondents.

A relatively high number of respondents (over 50%) reported that they belonged to a DPO. This is not surprising, as most of the respondents were identified via DPOs. However, it can be assumed that far fewer persons with disabilities in any particular town belong to a DPO.

Including only respondents with disabilities is a limitation in the analysis of results.

The choice was made to include only (self-identified) persons with a disability in the survey, in order to reach the largest number of persons with disability as possible, within the budget available. While this is a unique situation, as it was possible to reach a large sample of persons with disabilities in 10 different towns, it also became a limitation as it is not possible to compare the data to persons without disabilities, and therefore not possible to ascertain whether the results stem from disability or due to the general (low) quality of life in SNNPR. Should this survey be repeated, a balance will need to be found between maximising the sample of persons with disabilities to be able to provide strong results and including as many different types of functional limitations as possible to disaggregate data by disability; as also collecting data on persons without functional limitations to be able to analyse the extent to which results are due to disability.

CONCLUSION

Quality of Life is generally measured by scoring a number of variables across a variety of life areas, in the case of this survey, by using the CBR Indicator Survey to score respondents in five areas of life: health, education, livelihood, social inclusion and empowerment. The findings of the survey demonstrate, among others, that persons with disabilities have inadequate access to health services and opportunities for education, work and community participation. Given that persons with disabilities in the SNNPR Region of Ethiopia scored relatively or extremely low in all five areas of life, it can be concluded that they tend to have a low quality of life.

The RDM programme is working with public and private organisations in SNNPR, with the aim of making their service delivery and development programmes inclusive for persons with disabilities. The survey results are proving to be very useful to the RDM team in making the case for disability inclusion to government officials and non-governmental organisation personnel. The RDM team aims to repeat the survey after a few years in the same communities, to see whether the quality of life of persons with disabilities has improved as a result of increased access to, and inclusion in, mainstream services as well as community participation.

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